

Luxembourg and Autism



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Historical Background

Luxembourg is a small trilingual (Luxembourgish, French, and German) European country with an estimated population in July 2017 of 594,130 inhabitants. It is however, the country in Europe with the highest population growth rate and the highest net migration rate (Central Intelligence Agency 2017).

There are no official figures as to the prevalence and incidence of autism in Luxembourg. However, according to the most recent statistics provided by Autism-Europe, autism spectrum disorder affects around 1 in 100 people (Autism-Europe 2017). Therefore, it is estimated that approximately 5,900 people live in Luxembourg with a disorder in the autism spectrum. With Luxembourg's birth rate at 11.5/1000 (Central Intelligence Agency 2017), it can also be estimated that 68 new cases of autism appear each year in the country.

Services dedicated to people with autism started to appear in Luxembourg in the 1980s and have since then increased substantially. The first organization dedicated to autism in Luxembourg was established in 1981 by the initiative

of Gilbert Huyberechts, the father of a child with autism and later also the president of Autism-Europe (from 1989 to 2000). This not-for-profit organization, the *Société Luxembourgeoise pour l'Aide aux Personnes Autistiques* [Luxembourgish Society for the Help of Autistic People], which in 1996 changed its name to *Autisme Luxembourg asbl*, was composed of parents, professionals, and supporters. This society had as its aims to create, develop, and manage preventive and curative measures, as well as to put in place educational and accommodation centers, and to search for a continuous integration of people with autism.

To fulfill one of its aims – to develop educational measures for people with autism – the *Société Luxembourgeoise pour l'Aide aux Personnes Autistiques* created in 1982 educational classes for children with autism within a mainstream elementary school. This initiative was audacious at a time when disabled children attended exclusively special education schools. In 1988, the government created an educational structure, the *Institut pour Enfants Autistiques et Psychotiques* [Institute for Autistic and Psychotic Children] and the classes became part of the *Service de l'Éducation Différenciée* [Special Education Service] of the Ministry for National Education. However, most of the classes remained as they were since the beginning – in mainstream schools. The aim of the *Institut* was to provide children and adolescents with autism with an adequate education, social, and professional

integration. For this, the special education classrooms insured an education adapted to their needs and implemented speech and psychomotor therapy.

To foster the personal development of people with autism, in 1989 the *Société Luxembourgeoise pour l'Aide aux Personnes Autistiques* also created the *Centre d'Intégration et de Récréation pour Personnes atteintes d'Autisme* (CIRPA) [Integration and Recreation Center for People with Autism] which offered specialized assistance and support to the needs and capacities of people with autism across their life through the organization of daily activities. In addition to the CIRPA, and to respond to a need of professional development of adults with autism, in 1991 the *Société Luxembourgeoise pour l'Aide aux Personnes Autistiques* created the cooperative society *Peter Pan*, which promoted the training and social integration of adults with autism in a protected work environment. The cooperative society *Peter Pan* has since then been dissolved.

Led by the initiative of Gilbert Huyberechts and a group of parents of children with autism, in 1996 the *Fondation Autisme Luxembourg* [Autism Luxembourg Foundation] was created with the support of the *Société Luxembourgeoise pour l'Aide aux Personnes Autistiques*. The *Fondation Autisme Luxembourg* had as aims to develop the capacities of autistic people and to provide them with a dignified life. To achieve this, they set as aims to (a) create, develop, and manage preventive and curative measures such as educational and accommodation centers for children, adolescents, and adults with autism; (b) facilitate the integration of people with autism in all educational, socio-cultural, and professional domains; (c) create and maintain a consultation service as well as a center for training and information for the parents of people with autism; and (d) facilitate research on autism.

In 2000, a not-for-profit parental association, the *Association des Parents de Personnes Atteintes d'Autisme de Luxembourg* [Association of Parents of Persons with Autism from Luxembourg], was created to protect the rights of people with autism and their families and to help and support them. Additionally, the association

aimed to improve the care services of people with autism throughout their life by facilitating and accentuating the dialog between families and policy makers and to sensitize the general public to better integrate people with autism in the educational, socio-cultural, sportive, and professional domains.

As one of the most recent measures put in place to improve the services offered to people with autism and their families, in 2009 the *Unité Autisme* [Autism Unit] was added to the services proposed by the *Service National de Pédiopsychiatrie du Centre Hospitalier du Luxembourg* [National Service of Child Psychiatry from the *Centre Hospitalier du Luxembourg*]. The service exists since 1995 and includes a consultation unit, a hospitalization unit, and a day care center. The aim of the creation of the *Unité Autisme* was to diagnose autism, support the families, and provide continued care for young children with autism.

Legal Issues, Mandates for Service

In Luxembourg, there are no laws or mandates specific to autism. However, there have been several laws and legal measures that have had an impact on the rights and quality of life of people with autism.

Regarding education, two laws had a major impact for people with autism. In 1973, a law was approved for the right of disabled children, who could not attend mainstream schools, to receive education at a special education school. Until that law was voted, disabled children were often excluded from receiving a formal education. In 1994, the law of 1973 was modified to encourage as much as possible the inclusion of disabled children in mainstream education. Under these laws, children with autism have the right to a formal education and can receive their education either at a special education school, such as the *Institut pour Enfants Autistiques et Psychotiques*, or at a mainstream school, or share their weekly school time between special and mainstream education. At the mainstream education, special arrangements such as having the support of a

special education teacher in the classroom for a certain amount of hours per week is also an option. Upon request of the teacher or the parents, an inclusion commission recommends the type of education best indicated for the child. However, parents have the final decision regarding the type of education and care that their child will receive.

Regarding health care, the law of 1998 and its amendment in 2005 addressing the creation of a dependence care insurance has had a major impact on the services and type of care people with autism can receive from the government. In order to receive special care from the dependence insurance, four main conditions need to be met: (a) to be dependent (i.e., to need help for personal hygiene, nutrition, and mobility), (b) to need the assistance for at least 6 months, (c) to require assistance for at least 3.5 h per week, and (d) that the need for assistance is a consequence of illness. The *Cellule d'Évaluation et d'Orientation de l'Assurance Dépendance* [Evaluation and Orientation Unit from the Dependence Care Insurance] assesses requests, advises regarding the existence of dependence, and determines the care and support provided to the person or the caregiver at different levels. The intensity of care and support is adapted according to the level of dependence of a person on someone else. Children younger than 8 years old are compared to a developmental chart corresponding to autonomy capacities acquired at different ages. Children older than 8 years old, adolescents, and adults are compared in terms of autonomy to an adult. The support can be reflected, among other things, on the attribution, substitution, reduction, or increase of the support given; on the proposal of reeducation or re-adaptation measures; on the type and amount of professional care provided; on the monetary support given to finance support not provided by a professional service; and on the support given to the family or caregivers.

Concerning the work conditions of adults with autism, two laws have had an impact on the employability and fair compensation of work. In 2003, a law was approved regarding the right of disabled people to work and to receive a salary equivalent to the national standards. Under this law, people with autism, presenting difficulties which impair their employability, should receive

at least the national minimum wage or the standard salary for the type of work performed that it be in sheltered workshops or in the mainstream job market. Based on an evaluation by the Medical Commission and the advice of the Orientation Commission, the government pays a part of the person's salary equivalent to the assessed percentage of the person's handicap and the remaining is paid by the employer. In 2011 the law of 2003 was amended to stipulate that the government pays the totality of the salary of a disabled person working in sheltered workshops. Additionally, under these laws, the Orientation Commission can decide whether a person with autism can receive free of charge support in orientation, training, re-education, professional integration and reintegration, initiation to the job market, and support for apprenticeships.

Finally, regarding special juridical statuses of disabled people, the law of 1982 on the rights of incapacitated adults provides legal protective measures for people who due to a reduction of their mental capabilities are unable to comply with legal acts. The law foresees three protective regimes (from less to more protective measures): (a) safeguard justice clauses, (b) advice and support by a legal guardianship, and (c) representation by a legal guardianship.

Overview of Current Treatments and Centers

In Luxembourg, services and centers dedicated to people with autism and their families are nowadays varied and spread through the individual's entire lifespan. They range from diagnostic services, treatment and support measures, education, professional integration and training, leisure activities, assistance, and housing. Due to the small size of the country, services are nationally governed and common to the whole country. Services are often centralized around the country's capital but some services have branches in different regions to facilitate access to people.

Diagnosis

There are two institutions that diagnose autism in Luxembourg. The *Unité Autisme* at the *Centre*

Hospitalier du Luxembourg diagnoses children until the age of 6 years and prioritizes the early diagnosis of children before the age of 18 months using a neurodevelopmental and environmental approach. To achieve this, the unit is active in bringing awareness about autism to professionals. They provide training to pediatricians as well as to professionals working in services dedicated to early screenings of children's health and development. This collaboration enables an early screening of autism and families are redirected towards the *Unité Autisme* for further assessments and orientation. In 2016, the *Unité Autisme* had 37 new cases for consultation (Unité Autisme 2017). The *Fondation Autisme Luxembourg* performs autism diagnosis to children, adolescents, and adults using a multidisciplinary approach and with a variety of psychological, educational, functional, and medical assessments. The *Fondation* is also often asked to verify previously obtained diagnosis. In 2016, the *Fondation* performed 37 new diagnostic assessments, from which 17 were diagnosed in the autism spectrum, 11 did not fulfill the criteria for an autism diagnosis, and the remaining 9 were ongoing assessments (Fondation Autisme Luxembourg 2017).

Treatment and Support

Both the *Unité Autisme* and the *Fondation Autisme Luxembourg* additionally provide support and guidance to the families by offering services themselves and by re-orienting families to other services. The *Unité Autisme* offers group psychotherapy for children and therapeutic interviews with the families. In 2016 the *Unité Autisme* followed 141 children and their families (Unité Autisme 2017). The *Fondation Autisme Luxembourg* offers support to children, adolescents, and adults with autism regardless of their abilities or difficult behaviors, as well as to their families and professionals working with them. This psychosocial and psychoeducational support comprises home help and advice to parents on strategies to implement at home, learning resources, and individual assistance on hygiene, mobility, and nutrition. They also work with siblings and peers, and frequently offer information sessions about autism to professional working with people with

autism. Additionally, the *Fondation* helps families in the setting up of medical care, obtaining assistance from the care insurance and other allowances that are foreseen in Luxembourg's health and social systems, as well as in obtaining appropriate care through other existing services. In 2016, the *Fondation* received 469 requests for support throughout its service in "diagnosis, support, and training" comprising new and follow-up cases as well as requests from professionals (Fondation Autisme Luxembourg 2017). Since 2010, an increase of about 20% in requests for diagnosis is observed each year and more than 40% of the requests concern people with autism without intellectual disability.

Education

In the education side, the *Institut pour Enfants Autistiques et Psychotiques* currently insures the education of 71 children and adolescents with autism aged from 4–18 years old at different educational levels, who due to their specific learning needs cannot attend mainstream education classrooms. The main aim of the *Institut* is to be as inclusive as possible and is thus composed of 11 different classrooms from which the majority are special education classrooms integrated within mainstream education schools. There are five classes in elementary schools and two classes in secondary schools. Additionally, there are four professional propaedeutic classes at the *Institut* that provide training preparing students older than 12 years for a profession. Students with autism who do not attend special education classes can also receive support for their special needs within the mainstream educational system. At the elementary school level, this support can be obtained by having special education teachers working in the classroom with the child. This teacher works in close collaboration with the other teachers and the parents. At the secondary school level, an inclusion commission advises adaptations for the student's needs such as technological or person support in class and develops an individualized education program in consortium with the teachers and parents when the student is not able to follow the regular academic program rhythm. With a restructuring of the

Special Education System, the *Institut* will change its name to *Centre pour le développement des enfants et jeunes présentant un trouble du spectre de l'autisme* [Center for the development of children and youth with an autism spectrum disorder] and will become one of eight Specialized Psychopedagogy Competence Centers in Luxembourg. This center will provide a specialized and multidisciplinary educational support with trained professionals to children and youth with autism.

Professional Integration and Training

There are different services in Luxembourg to support the professional development of people with autism. The *Fondation Autisme Luxembourg* offers a small educational farm and five sheltered workshops to those who use their day care centers: the kitchen, the laundry, the garden, the do-it-yourself workshops, and sports. These activities ensure learning retention and development of competences, promote verbal and non-verbal communication, provide a stimulating daily social environment, and a commendable daily work activity. These activities are dedicated to people with autism aged 16 years or older who due to their difficulties and challenging behaviors cannot work in other existing sheltered workshops. Additionally, the *Fondation* is active in the integration of people with autism in the regular job market by providing support in the process of hiring, providing training to the company, as well as coaching those looking for a job.

Autisme Luxembourg asbl offers professional training for people with autism older than 16 years old, who have finished their compulsory school or who have difficulties finding a job due to their needs. An individualized training program is established based on the needs of the persons and prepares them for a professional activity. The training lasts 2–3 years and aims at the acquisition and improvement of personal skills, autonomy, as well as teaching appropriate attitudes and behavior during work. The training prepares people with autism for an active work life either in a sheltered environment or in the regular job market. *Autisme Luxembourg asbl* also offers different sheltered workplaces for people with autism who can work in a variety of domains such as the development of books and mobile

applications, digitalization of printed documents, printing shop, gardening, art and ceramics, cooking, etc. People with autism who integrate the regular job market can also receive assistance to find and keep a job from *Autisme Luxembourg asbl* through their ambulatory intervention center. This service aims at providing social support on an as-needed basis to individuals with autism who live independently or semi-independently.

Leisure Activities

Regarding leisure activities, both the *Fondation Autisme Luxembourg* and *Autisme Luxembourg asbl* offer adapted activities to people with autism of different ages. The *Fondation Autisme Luxembourg* offers on a daily basis during the entire year extracurricular activities for children. These include indoor activities such as crafts, cooking, individual desk-based learning, sensory space, games, and relational games or outdoors activities such as walks, swimming, visits to parks, and attendance to shows. The *Fondation* also organizes regular holiday camps for people with autism of all ages (children, adolescents, and adults) throughout the entire year.

In their day care center and leisure center, *Autisme Luxembourg asbl* offers adults with autism who are not able to exercise any professional activity different occupational activities such as games and puzzles, sportive activities such as walks and swimming, socio-pedagogical and therapeutic activities such as snoezelen and musical sessions, as well as regular outings.

Assistance

Social, physical, and mental health assistances are provided by the *Fondation Autisme Luxembourg* throughout their different services such as the support service (see “[Treatment and Support](#)” section).

Autisme Luxembourg asbl provides a home help service to keep people with autism in contact with others and to help them build a social network of support with the aim of maximizing their autonomy and well-being. They also provide a care and health service that helps centralize their information and manage the contact between the person with autism, their families, and different health-care providers (dentist, psychiatrist,

physical therapist, psychotherapist, etc.). Finally, a consultation service is also offered which is composed of a multidisciplinary team that develops interventions in the form of consultations, interviews, individual therapy sessions, group therapy sessions, information sessions, and work with the families.

Housing

Currently, the *Fondation Autisme Luxembourg* has two residential centers for people with autism. One of the centers has three homes that accommodate 20 people with autism aged from 20 to 65 years living in small groups. The other residence accommodates 24 people with autism presenting with different levels of independence, living in three groups of 6–7 people each. In this center, one of the homes is generally dedicated to individuals aged 20–60 years, another home is specifically dedicated to elderly people who have reduced mobility, and the other is specifically dedicated to younger people with autism such as adolescents. Both centers have permanently at least two respite care rooms for temporary admissions to meet the needs of families when required and for emergency cases when needed. This service is available for people with autism of all ages and levels of abilities regardless of their degree of difficult behaviors.

Autisme Luxembourg asbl offers three types of housing support for adults with autism. They have three centers for supported housing in which residents live autonomously and the association insures through their home help service that the person stays in contact with others in their community and neighborhood, helping their integration, autonomy, and well-being according to their abilities. *Autisme Luxembourg asbl* also has a residence for five people who either work in their sheltered workshops or who attend the day care center. The stay at this residence is intended as a transition period where residents are prepared to a more autonomous life where they can manage their budget and take care of themselves and the place where they live. Finally, *Autisme Luxembourg asbl* also has a residence for substantially dependent people with autism. That residence houses ten people who need a close socio-

pedagogical support in their daily life activities. The residence also includes one respite care unit for emergency cases.

Other Non-autism Institutions

In addition to the different services that are dedicated exclusively to people with autism, there are also other institutions and services in Luxembourg dedicated to support people with educational difficulties or disabilities, who can provide help to those with autism. In the support of young children, the *Service de Rééducation Précoce – Hëllef fir de Puppelchen* [Early re-Education Service – Help for the Babies] provides services of observation, assessment, screening, guidance, treatment, and reeducation to children up to the age of 4 years. Their multidisciplinary team offers physical, occupational, and speech therapy as well as playgroups to improve children's autonomy and psychosocial abilities. The *Service d'Intervention Précoce Orthopédagogique* [Service of Early Intervention and Orthopedagogy] provides services to children up to the age of 6 years on psychological assessment and testing of abilities, difficulties, and delays, as well as socio-pedagogical and therapeutic support, and psychological interventions for the children and their parents. Additionally, parents can seek treatment, therapy, and support, as well as diagnostic advice on autism from private sector professionals such as pediatricians, psychiatrists, and psychologists.

Associations such as the *Tricentenaire asbl*, the *Association de Parents d'Enfants Mentalement Handicapés* [Association of Parents of Mentally Handicapped Children], the *Ligue HMC*, or companies such as *elisabeth* that act in the social domain provide therapeutic support, day care centers, leisure activities, housing, professional training, and sheltered work structures to disabled people. Finally, *Info-Handicap Luxembourg* informs, orients, and provides support to disabled people, their families, and professionals. The service also provides legal assistance to support people in the access to services, to protect their rights, and to assist them in case of discrimination.

Overview of Research Directions

A research group conducts research on autism at the *Institute for Health and Behavior* at the *University of Luxembourg*. The research is centered on understanding different aspects related to the emotional difficulties of children with autism (e.g., Costa et al. 2017c) and the link between these to the development of internalizing and externalizing problems as well as to difficulties within the family (e.g., Costa et al. 2017a). The group is currently working on the development of technology-based interventions to teach emotional ability to children with autism (e.g., Costa et al. 2017b). Additionally, other works such as Bachelor's and Master's theses about autism have been conducted in collaboration with the University of Luxembourg as well as with other institutions in Luxembourg.

Overview of Training

The *Fondation Autisme Luxembourg* provides training to professionals working with people with autism as well as to parents and interested persons. The *Fondation* also offers the "Earlybird" training under the license of the National Autistic Society from the United Kingdom, to parents of children with autism under the age of 6 years. Training sessions are organized on a regular basis and are provided either at the *Fondation* or in the framework of the trainings offered by the *Institut de Formation de l'Éducation Nationale* [Training Institute from the National Education]. The *Fondation* also acts as a training platform for people learning to become social workers and the trainings provided by the *Fondation* are governmentally recognized. Additionally, the *Fondation* organizes regular parent-professional meetings where parents are informed of state-of-the-art practices and advances related to autism and where parents can ask questions and exchange information with professionals. In these meetings, people with autism without intellectual disability often take part as trainers or facilitators of the training sessions. In addition, the *Unité de Formation et d'Éducation Permanente* [Training and

Permanent Education Unit] also offers training to professionals working with people with disabilities, specifically in the social and support domains.

Social Policy and Current Controversies

Currently, the main challenges about autism in Luxembourg are related to parents' and professionals' concerns regarding a more comprehensive and clearly structured care of people with autism. The services have substantially increased since the 1980s and different structures now exist to support people with autism and their families. However, some aspects still need to be considered in order to further develop the offered support and services.

One of the challenges, from which some of the others stem, is a need for an overview regarding the situation of autism in the country. Autism prevalence and incidence in Luxembourg is unknown and a comprehensive system reporting the education and care that diagnosed people receive is still to be developed. Related to that issue, is a difficulty in the concertation of efforts among the different institutions dedicated to autism. Institutions cooperate among themselves to provide the better care for the person and the family but the absence of a national plan for autism, as is the case for many European countries and is the case for other societal challenges in Luxembourg such as suicide prevention and rare diseases, makes it difficult for the institutions to develop a long-term service adapted to the real needs of the country and coordinate their efforts.

Additionally, a common problem faced by the different institutions is a lack of resources to deal with the increasing number of people requesting a diagnosis and the diagnosed who need care and adapted structures. Even though several structures exist, they are not sufficient for all those requiring support. There is a long waiting list for diagnosis and an early diagnosis, even though given priority, cannot always be guaranteed. This hinders the implementation of early interventions which are a determinant factor to the outcomes of the child and the family. Furthermore, there are no intensive intervention

programs dedicated to work on children's abilities that can foster their development and increase the chances of better life outcomes and well-being. There are also a limited number of structures and places that provide adapted support, care, and accommodation to people with autism which cannot answer to all the requests. For instance, a living structure able to accommodate children and adolescents with autism with severe behavior problems, which can cause significant distress and loss of economic power to the family due to the need of a parent remaining constantly at home, is still inexistent.

In Luxembourg, different services, structures, and measures have been developed in the past decades that had an impact in improving the lives and well-being of people with autism and their families. Nowadays, the country strives to continue to provide quality services that are accessible to all people with autism and their families. To achieve this and answer to the needs of Luxembourg's growing population more services as well as the scope of the existing ones need to be expanded.

See Also

- ▶ [Association des Parents de Personnes Atteintes d'Autisme de Luxembourg \(APPAAL\)](#)
- ▶ [Autisme Luxembourg asbl](#)
- ▶ [Centre Hospitalier de Luxembourg \(CHL\) – Centre de jour Pédopsychiatrique et Unité Autisme](#)
- ▶ [Fondation Autisme Luxembourg \(FAL\)](#)
- ▶ [Helpline Assurance Dépendance: \(+352\)247-86060](#)
- ▶ [Institut pour Enfants Autistiques et Psychotiques \(IEAP\)](#)
- ▶ [Ministère de l'Éducation nationale, de l'Enfance et de la Jeunesse \(MEN\) – Service de l'Éducation Différenciée](#)
- ▶ [Ministère de la Famille, de l'Intégration et à la Grande Région \(MFI\)](#)
- ▶ [Ministère de la Sécurité Sociale \(MSS\) – Cellule d'Évaluation et d'Orientation de l'Assurance Dépendance](#)
- ▶ [Service d'Intervention Précoce Orthopédagogique \(SIPO\)](#)
- ▶ [Service de Rééducation Précoce – Hëllef fir de Puppelchen \(SRP\)](#)
- ▶ [Université du Luxembourg – Institute for Health and Behavior](#)

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